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Award Number: DAMD17-01-1-0546

TITLE: Barriers to Early Detection of Breast Cancer Among
African-American Females Over Age of 55

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REPORT DATE: October 2002

TYPE OF REPORT: Annual

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

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REPORT DOCUMENTATION PAGEForm Approved
OMB No. 074-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503

1. AGENCY USE ONLY (Leave blank)		2. REPORT DATE October 2002	3. REPORT TYPE AND DATES COVERED Annual (10 Sep 01 - 9 Sep 02)	
4. TITLE AND SUBTITLE Barriers to Early Detection of Breast Cancer Among African-American Females Over Age of 55			5. FUNDING NUMBERS DAMD17-01-1-0546	
6. AUTHOR(S) Virginia J. Smith, Ph.D.				
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Lincoln University Lincoln University, Pennsylvania 19352 E-Mail: vsmith@lu.lincoln.edu			8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012			10. SPONSORING / MONITORING AGENCY REPORT NUMBER	
20030226 077				
11. SUPPLEMENTARY NOTES				
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited.				12b. DISTRIBUTION CODE
13. ABSTRACT (Maximum 200 Words) This exploratory study to identify barriers to early detection of breast cancer among African-American females over the age of 55 was designed to result in the articulation of hypotheses for further study. Preliminary findings are based only on the in-depth review of the literature that was conducted. This review confirmed that there are disparities in rates of early diagnosis of breast cancer among African-American women between the ages of 55 and 70. Also, it showed that there are still unexplained factors of late diagnosis of breast cancer among African-American females. Additionally, only a few studies address the cultural context issues and those that have provided insight have used qualitative methods. Based on the findings from the literature review, a semi-structured interview protocol was developed to explore beliefs and practices around breast cancer and breast cancer screening among a small sample of up to 25 African-American breast cancer survivors over the age of 55.				
14. SUBJECT TERMS Breast Cancer, African-Americans				15. NUMBER OF PAGES 18
				16. PRICE CODE
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited	

NSN 7540-01-280-5500

Standard Form 298 (Rev. 2-89)
Prescribed by ANSI Std. Z39-18
298-102

**Barriers to Early Detection of Breast Cancer among African-American
Females
Over Age 55**

**Annual Report
(September 10, 2001-September 9, 2002)**

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Appendix Literature Review

Barriers to Early Detection of Breast Cancer among African-American Females Over Age 55

Annual Report (9/10/01 – 9/9/02)

INTRODUCTION

This exploratory study to identify barriers to early detection of breast cancer among African-American females over the age of 55 was designed to result in the articulation of hypotheses for further study. Based on an in-depth literature review, a semi-structured interview protocol was developed to explore beliefs and practices of the respondents around breast cancer and breast cancer screening. Presently, the study protocol is still in the review process for approval of enrollment of human subjects. This report presents the results of the literature review and the tentative study protocol. A no-cost extension has been requested. It is estimated that the study will be complete by September 9, 2003.

BODY

The specific tasks in the workplan for this study are:

1. Conducting an extensive literature review
2. Developing an interview protocol
3. Outlining a sampling strategy
4. Scheduling preliminary interviews with potential subject to review study format and discuss informed consent procedures
5. Conducting up to 25 in-dept interviews
6. Reviewing and coding transcripts of interviews and coding for analysis
7. Conducting analysis in NUDIST
8. Interpretation of data
9. Preparation of manuscript(s) for submission to peer review journals
10. Preparation of PowerPoint presentation of findings of study
11. Preparation of final report, including recommendation of specific hypotheses for future study

The literature review has been completed and items 2-3 above have been completed. The remaining items have not been accomplished because the protocol has not been approved for enrollment of human subjects.

A summary of the literature review is enclosed as an Appendix of this report.

KEY RESEARCH ACCOMPLISHMENTS

A comprehensive review of relevant literature was conducted. The literature review confirmed that the mortality rates from breast cancer are higher among

African-American women that for any other racial/ethnic group of American women (approximately 28% higher than for white women). Additionally, once diagnosed, African-American women below the age of 70 are less likely to survive for five years beyond diagnosis. Moreover, the literature review confirmed that differential breast cancer mortality rate between African-American and white women is related to later diagnosis at less treatable stages. Other findings of the literature review include:

- Economic access to health care and insurance is associated with late stage diagnosis; however in some studies where health insurance is held constant, African-American women were still diagnosed at later stages.
- Some studies indicated that in lieu of regular mammography screening, African-American women have more incidental breast self-examination-discovered cancers than do white women.
- Socio-economic status was confirmed as a factor in late stage diagnosis, although it was suggested that racial disparities in breast cancer are smaller than when SES is examined alone.
- Breast health care and breast cancer are interwoven with beliefs, attitudes, and health care practices that are part of a cultural context, although there were only a few studies addressing this.
- Lower educational attainment is associated with late-stage diagnosis, but studies have not found educational status to be an independent predictive factor of late stage diagnosis.
- Several scattered programs have been successful in facilitating early diagnosis of breast cancer among African-American. Some of these have been based on various levels of understanding of cultural context.

REPORTABLE OUTCOMES

There are no reportable outcomes to report at this time since authorization to enroll and interview human subjects has not been attained.

CONCLUSIONS

Preliminary conclusions are based only on the literature review. They are as follows:

- There are still unexplained factors of late diagnosis of breast cancer among African-American females
- Few studies address the cultural context issues and those that have provided insight have used qualitative methods.

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Barriers to Early Detection of Breast Cancer among African-American Females Over Age 55

SUMMARY OF LITERATURE REVIEW

INTRODUCTION

In 2001, the most common cancers among African American women will be breast cancer (31%). Breast cancer is the second leading cause of death among African American women, exceeded only by lung cancer. In 2001, approximately 19,300 new cases are expected among African American women, while 5,800 are expected to die of breast cancer (American Cancer Society, 2000). Most significantly, African American women have higher mortality rates from breast cancer than any other group of Americans. The mortality rate for African American women is 35.7%; white women is 27.3%; Hispanic women is 16.8% (National Vital Statistics System, 1998)

INCIDENCE OF BREAST CANCER

Breast cancer is the most common form of cancer among women in the United States. The incidence of breast cancer has been rising over the past two decades, while mortality has remained stable. Although much of the increase is attributable to increased screening by mammography and physical examination, screening alone does not explain this increase. The age-adjusted incidence of invasive breast cancer indicates in descending order that white, African-American and Hawaiian women have the highest rates of breast cancer. In situ breast cancer occurs at much lower rates than invasive breast cancer, but has similar racial/ethnic patterns as does the invasive cancers (SEER, 2001).

Age specific incidence rates for invasive breast cancer present similar ethnic patterns. Among women aged 30 – 54 years, however, whites and Hawaiian women are similar, followed by African American women. Among women aged 55-69 years and 70 years and older, age specific incidence rates follow the same ethnic patterns as for those aged 30-54 years. In situ breast cancer incidence among women aged 30-54 years and 70 years and older is highest among white non-Hispanic women, followed by Japanese women, and white (total) women. At ages 55-69 years, in situ breast cancer is highest among white women, followed by Japanese women and African American women (SEER, 2001).

Inflammatory breast cancer is a clinical and pathologic entity characterized by rapid disease progression and poor diagnosis. Although it accounts for less than 5% of all invasive cases of breast cancer diagnosed in the US each year, it is one of the most lethal types of breast cancer with incidence higher in African American women than in white women. Increased risk of inflammatory breast cancer has been linked to high body mass (National Cancer Institute, 2001).

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Important risk factors for female breast cancer include early age at onset of menarche, late age at onset of menopause, first full-term pregnancy after age 30, a history of premenopausal breast cancer for mother and a sister, and a personal history of breast cancer or of benign proliferative breast disease. Obesity, nulliparity and urban residence also have been shown to be associated with increased risk. From a preventative perspective, physical activity is suggested as a mitigating factor for breast cancer incidence (SEER, 2001).

Select risk factors are particularly relevant for African American women. By 1998, 64% of African American women were overweight and 32% were characterized as obese (American Cancer Society, 2000). Data from the 1998 Behavioral Risk Factor Surveillance System indicate that 40% of African American women reported no leisure-time physical activity (Surgeon General, 1996). Yet, findings suggest that strenuous physical activity in early adulthood is associated with reduced risk of breast cancer in African American women (Adams-Campbell, et al., 2001).

DISPARITY IN MORTALITY RATE

Notwithstanding the national stabilization rates of mortality from breast cancer, cancer mortality among African American women is approximately 28% higher than white women (American Cancer Society, 2000). Moreover, African American women who are diagnosed with breast cancer are less likely than white women to survive five years after diagnosis, the rate among African American women is 71%, compared to 86% among white women (Ries, et al., 2000).

In the age groups of 30-54 years and 55-69 years, African American women have the highest mortality rates. In the 70 years and older age group, the mortality rate for white women exceeds that for African American women (SEER, 2001).

Multiple studies have established the fact that the differential breast cancer mortality rate between African American and white women is due to the fact that a larger percentage of African American breast cancers are diagnosed at later, less treatable stages (SEER, 2001; Baquet & Comiskey, 2000; Joslyn & West, 2000; Chu, et al., 2000; Aziz, et al., 1999; Phillips, et al., 2001; Polednak, 2000.)

It is crucial to identify and understand the factors that are associated with late diagnosis breast cancer for African American women. The factors are complex and interrelated. The following studies indicate that the health care system, economic access and its practices as well as demographic factors are associated and interrelated with late-stage breast cancer diagnosis:

Role of the Health Care System

Economic access to health care, insurance, is associated with late stage diagnosis. Studies indicate that persons lacking health insurance and persons insured by Medicaid

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are more likely diagnosed with late stage breast cancer (Rimer, et al., 1996; Roetzheim, et al., 1999). Since African American women are more likely to not have insurance or to rely on Medicaid entirely or as part of their insurance package, insurance status is one factor associated with their late stage diagnosis.

However, racial differences in late stage diagnosis are not explained entirely by insurance coverage (Roetzheim, et al., 1999). When type of coverage is held constant as it was in the Military Health System study (Bibb, 2001) and in the Josephine Ford Cancer Center managed care study (Yood et al., 1999), African American women were still diagnosed at later stages than were white women. In the Military Health System Study, the African American women were of lower SES than their white counterparts.

An examination of health care system practices, per se, reveals other factors associated with late stage diagnosis. Studies have explored the role of physician recommendation for mammography, a precursor strongly associated with mammography use. A study of single, older women, 65 years and older residing in Nashville, TN housing projects showed that access to regular medical care and receiving a physician's recommendation are strongly associated with mammography among these women (Zhu et al., 2000).

O'Malley's et al. (2001) study of a rural older women found that recommendation for mammography was 10% higher for white women than African American women. Further, mammography was more frequent among women who had a regular physician and health insurance. Recommendation was less frequent among women who were more vulnerable and older, and had low formal education and low income. Although African American women received fewer recommendations for mammography than white women, in this study, racial differences disappeared when SES was controlled.

Another study produced finer grain information on the impact of type of health care practitioner providing the recommendation. It was found that low income African American women who were referred for a mammography by a physician's assistant or nurse practitioner were less likely to miss their appointments than women referred by a physician (Crump, 2000).

In lieu of regular mammography screening, it appears that African Americans particularly those of low SES have more incidental breast self-examination-discovered cancers than do white women (Bibb, 2001; Tessaro et al., 1994). This finding, leads Bibb (2000) to conclude that the most significant predictors of late-stage diagnosis were means of discovery and the length of time between discovery and diagnosis. Generally, breast self-examination- discovered cancers are in later stages than those discovered through mammography. African American women who avoid the medical system or for whom the medical system fails to recommend screening are more likely to be diagnosed at later, often untreatable stages of breast cancer.

In addition to mammography recommendation, it is suggested that there is a difference in actual treatment of cancer for African American women (Chu et al., 2000). Breen's et al. (1999) study results found that thirty-six percent of the patients with late stage disease did

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not receive minimum expected therapy compared to four percent of the patients with early stage disease. Older women and women with no usual source of care were significantly less likely to receive minimum expected therapy. Overall, 21% of African American women did not receive minimum expected therapy compared to 15% of white women. Furthermore, minorities with cancer often suffer more pain due to under medication. Nearly 62% of patients at institutions serving predominately African American patients were not prescribed adequate analgesics (Ross, 2000).

Focusing on the one-to one relationships between health care personnel and African American women, positive attitudes of health care personnel are important to patients. Gates's et al. (2001) ethnographic study indicates that professional caring supports women to seek breast cancer diagnosis and treatment, whereas non caring related to a 'wait and see' attitude of health care providers encourages women to delay early diagnosis.

The health care system is not color blind. African American women often experience the health care system and its personnel as discriminatory, whether or not the motives are racially driven or are clouded by age and gender bias, low income, lack of or low reimbursement insurance coverage (Clark, 2001). Differentials in frequencies of mammography recommendations and treatment regimes between white and African American women are viewed as manifestations of health care personnel's negative attitudes and beliefs about African American women. These issues create a lack of trust of the medical system to do what is best for African Americans and their families (Frederick Schneiders Research, 1999). Given this context, it is not difficult to understand African American women's reluctance to take full advantage of the health care system, especially in availing themselves of early diagnostic procedures and follow-up on physician recommendations. Although not documented experimentally, it is likely that the African American women's wary perception of the health care system is an important factor associated with their late stage diagnosis of breast cancer.

DEMOGRAPHIC FACTORS

SES

As suggested by many studies, SES is a critical factor in late stage diagnosis. Late-stage breast cancer is more likely to be diagnosed in African American women of low SES (Bibb, 2000; Crump et al., 2000). Correspondingly, breast cancer mortality is higher for women of lower SES (Baquet & Commiskey, 2000). Since African American women are likely to have incomes below poverty level (Haynes & Smedley, 1999), the association of low income with late-stage diagnosis and high mortality rates for breast cancer is particularly relevant for this population. Although, it is suggested that racial disparities in breast cancer are smaller than when SES is examined alone, disparities still exist (Baquet & Commiskey, 2000).

Educational Attainment

Lower educational attainment is associated with late-stage diagnosis (Rimer et al., 1996; O'Malley et al., 2001), but studies have not found educational status to be independent

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predictive factor of late stage diagnosis. Rather, studies that examined educational attainment, combined it with other factors such as income. Nonetheless, since African American women have lower educational attainment levels than do white women, the association of low education and late-stage diagnosis is relevant to African American women.

Educational attainment or status is not to be confused with education about breast cancer. These are two different factors. One cannot assume that higher educational status incorporates knowledge about breast cancer. Nothing in the literature supports this assumption.

However, lack of education about breast cancer is associated with late diagnosis in a number of studies, whereas education about breast cancer appears to be factor and strategy that increases mammography use. (See Sections about Cultural Context and Programs for Early diagnosis)

Residence

There is an interaction between race and residence in late stage diagnosis. Rural African American women are diagnosed much later than are urban African American women or white women of either residence (Amey et al., 1997). In California, early diagnosis of breast carcinomas differed markedly not only by age, ethnicity, diagnosis year, but county of residence, as well (Menck & Mills, 2001).

Health care physical access in rural areas in most instances is more problematic than in urban areas. General access problems may exacerbate the factors of health insurance, physician practices and perceived discrimination that lead to late diagnosis.

Health care system issues and demographic factors are associated with late stage diagnosis of breast cancer of African American women and contribute to the disparity between them and white women. Many of these factors are interrelated. In some studies, contradictions emerge. However, most studies indicate that despite the impact of these demographic and health system focused factors, unexplained factors remain within the African American population that also contribute to late stage diagnosis for breast cancer.

CULTURAL CONTEXT

Breast health care and breast cancer are interwoven with beliefs, attitudes and health care practices that are part of a cultural context. An exploration of these beliefs and attitudes provide a rich informational source to understand late stage diagnosis of breast cancer among African American women. In particular, the few available qualitative studies yield significant insights.

A study of a general population of African American and white women found significant differences on all of the health beliefs about cancer. African American women were more likely to believe in chance, or to believe in powerful others for their health.

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Moreover, African American women underplayed their susceptibility to cancer, doubted the value of early diagnosis and tended to regard the diagnosis of cancer as inevitably leading to death. Although higher education status mediated these beliefs for white women, it did not for African American women (Barroso et al., 2000).

Phillip's et al. (1999) qualitative study sought to understand the beliefs, practices and attitudes related to breast cancer and breast cancer screening among low-income and middle-income African American women. Women from three employment groups comprised the focus group sample. Findings indicate that when cancer was discussed, the primary feeling in all groups was fear. Fear was a primary reason not to engage in screening. All participants stressed that breast cancer is seldom discussed within the community. Teachers felt that the secrecy may lead to African American women thinking breast cancer to be a white women's disease. Unemployed and service workers emphasized the role of violence in causing breast cancer, whereas teachers identified sex and injury as causal.

McDonald et al. (1999) studied the perceptions and knowledge about breast cancer among African American women residing in public housing. They found that breast cancer knowledge was poor. Women did not perceive themselves or a particular racial or economic group to be more susceptible to breast cancer, nor did they perceive breast cancer as a fatal disease. The women, by and large, endorsed the benefits of mammography and denied the relevance of commonly cited barriers to breast cancer screening. Yet, by using a different methodological approach, it was found that these women did indeed, perceive barriers to clinical breast examinations.

The study on single older women in Tennessee housing projects indicates that education on breast cancer, having living children and being involved with social activities were associated with use of mammography (Zhu et al., 2000). So although higher educational status may not mediate erroneous beliefs about cancer (Barroso, et al., 2000), education specifically about cancer may be predictive of increased mammography use.

A study by Crump et al. (2000) explored the factors related to noncompliance with screening mammogram appointments among low-income African American women. It found that women who missed appointments did so because of embarrassment, lack of symptoms, and forgetfulness.

In Mayo's et al. (2001) study of rural elderly women, fatalism was positively associated with increased age and decreased educational level. More significantly, fatalism was associated with noncompliance with mammography screening among African American women.

Through a qualitative study eliciting social and cultural themes related to breast cancer screening, it was found that for older African American women: other health concerns are of more concern than cancer, age is generally not recognized as a risk factor, fear of finding breast cancer and its social consequences are barriers to mammography, they tend to rely on breast self-exam rather than mammography, cost is more an issue of competing

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priorities than cost per se, the tradition is to go to the doctor for a problem, not prevention, and women in their own social networks are important sources of social support for health concerns (Tessaro et al., 1994). This qualitative study enables income to be viewed through a different lens. That is, it raises the question that in some situations, it may not be low income that drives decision about mammography use, but instead, the value one places on mammography within the larger issues of how to spend one's income.

Gates's et al. (2001) ethnographic study sought to understand the impact of caring for others on decision to delay diagnosis and maintain continuing treatment. Would time commitments to caring for other people delay diagnosis and treatment? The study indicated that caring for others is meaningful and promoting continued commitment to diagnosis and treatment, caring from others both generic and professional as supportive for the women to continue treatment, and non caring related to the "wait and see" attitude of healthcare providers and of women delaying early treatment as the reason for delay in seeking care.

Phillips' et al. (2001) phenomenological study of low-and middle-income women sought to describe the experience and meaning of breast cancer screening for African American women. The women spoke of their desire for a holistic approach to health that did not separate the breast from the rest of the body. This desire is indicated in the theme of minding the body, self and spirit, along with themes of relationships.

Critical themes emerge from exploring the impact on mammography use of African American women's beliefs and education about breast cancer. Although formal educational level appears not to influence beliefs and knowledge about breast cancer, specific education about breast cancer appears to be associated with higher mammography use. The second theme is that is that African American women hold beliefs and attitudes about breast cancer that are counter-productive to early and routine screening by mammography. These beliefs may be manifestations of their of lack of knowledge about breast cancer. Third, the theme of relationships with family and others, as well as being needed and depended upon by their significant others appear to be linked positively to mammography use.

IMPACT OF AGE

The demographic and health system factors associated with late-stage diagnosis are more pronounced with age. African American women are more likely to have lower incomes, no insurance or Medicaid insurance, have lower educational status, have less frequent referrals for mammography from physicians and rely more on self-examination than mammography than either the younger African American or the older white cohorts (O'Malley, et al., 2001; Menck & Mills, 2001; Ackerman, et al., 1992; Tessaro, et al., 1994). Further, they are more likely than other cohorts of women to hold belief patterns in opposition to early diagnosis (Mayo et al., 2001). Older African American women are at great risk for late diagnosis.

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PROGRAMS TO FACILITATE EARLY DIAGNOSIS

Several initiatives have been undertaken to increase mammography use by African American women. Recognizing the importance of natural networks in the African American communities, two projects sought to use these networks for education about breast cancer and the importance of early diagnosis through mammography. A California study (Derose, et al., 2000) recruited 50 – 80 year old African American, Latino and white women to participate in a mammography promotion program through their churches. It was found that an extended resource intensive period of relationship-building and community-based activities were necessary to conduct church-based programs effectively, particularly among older and ethnically diverse urban populations.

A creative California study sought to educate African American women about the importance of early detection of breast cancer through an educational program directed to their natural network, African American cosmetologists. The expectation was that the cosmetologists would inform and their clients about the benefits of routine screening and early diagnosis of breast cancer. Both cosmetologists and their clients demonstrated that despite their hearing the message from other sources, a substantial proportion had never realized breast cancer's high morbidity and mortality within their own community (Sadler, et al., 2000).

Recognizing the importance of income, access to health care systems and breast cancer education, a study reported in Boston sought to increase mammography rates among inner city non-Caucasian women 50 years and older by removing the barriers associated with cost and securing mammogram appointments. A peer delivered intervention, which consisted of a brief motivational interview, mammography referral at the time of the primary care visit and the scheduling of a next-day, free mammography appointment. The results were that 60% had kept the mammography appointment of which 69% were first time users. Of those who did not keep the appointment, 77% requested a "second chance" (Bernstein, et al., 2000). Although this study did not evaluate the importance of the peer motivational interview, this is a promising factor for later studies.

The NCI "Public Health Approaches to Breast and Cervical Cancer" initiative sought to change internal health care access mechanisms and provide outreach and education as ways of encouraging mammography use. Funding in North Carolina was instituted to improve the use of breast and cervical cancer screening among low-income, predominantly African American women age 40 and older. Strategies implemented included public health clinic in reach strategies (chart reminders, exam room prompts, in-service meetings, and patient-directed literature) and community outreach strategies (educational sessions, literature distribution, community events, media and church programs). In the city with the intervention strategies, the use of mammography increased from 31% to 56%. In the non-intervention city, increase was not significant.

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This study indicates that a multifaceted intervention can improve screening rates for breast cancer in a low-income population (Paskett, et al., 1999).

A study methodology of informing older women of their mammography benefits via a mailing proved successful. This study sought to publicize the Medicare subsidized biennial mammogram benefit. The intervention was a targeted mailing informing older women about the benefit. Mammogram use increased significantly among minority women in the experimental group. In fact, African American women were twice as likely to undergo screening relative to the women in the control group (Fox, et al., 2001).

On the other hand, there was minimal effect of patient reminders on the use of screening mammography in an urban health department primary care setting. Participants were predominantly African American, two-thirds were over the age of 50 and all had minimal health coverage. Letters directed to reminding women to contact either their primary care physician or the clinic directly to schedule a mammogram, had no greater impact than not receiving any letter at all (Simon, et al., 2001). Unlike the Medicare study that provided information about the low-cost Medicare benefit, this intervention was only a reminder of need for appointment.

Recognizing that African American women depend on breast self-examination, the Howard University College of Nursing, sought to reinforce self-examination and reinforce that it is an important component in an educational program. Their study targeted inner city elderly African American populations. The objectives of the study were to determine the breast cancer knowledge of subjects, their level of confidence when performing self-examination, and if individual instruction, one-to-one practice and feedback on performance made a difference in screening practices. They found that more intensive interventions sustain breast examination self-efficacy. No other results were reported (Adderley-Kelly & Green, 1997).

These programs indicate that education, particularly through natural networks and peers, removing barriers of cost and access to health care and revisions in the operations of health care sites can increase mammography use and other screening use by low-income African Americans, and in particular, the older cohort.

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APPENDIX

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